

Original citation:

Irving, G., Holden, J., Edwards, J., Reeve, Joanne L., Dowrick, C. and Lloyd-Williams, M.. (2013) Chronic heart failure guidelines : do they adequately address patient need at the end-of-life? International Journal of Cardiology, Volume 168 (Number 3). pp. 2304-2309. ISSN 0167-5273

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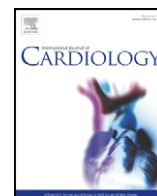
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Chronic heart failure guidelines: Do they adequately address patient need at the end-of-life? ☆☆☆

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ARTICLE INFO

Article history:

Received 12 September 2012

Received in revised form 8 January 2013

Accepted 18 January 2013

Available online 7 March 2013

Keywords:

Chronic heart failure

Guidelines

End-of-life

Primary care

ABSTRACT

Introduction: A number of international guidelines have been developed to support primary care clinicians improve the quality of care for patients with chronic heart failure at the end of life. The objective of this study was to undertake a systematic evaluation of such guidelines in relation to end-of-life care.

Methods: A systematic literature search of research databases and guideline clearing houses was undertaken. The selected guidelines were independently assessed by two researchers using the AGREE II quality criteria. A data-extraction framework was devised based on the holistic needs assessment tool of the Gold Standards Framework. The content of each guideline was then analysed using an approach similar to that used for thematic analysis.

Results: A total of 19 guidelines were included. Those guidelines with lower overall AGREE II scores covered fewer domains on the holistic needs assessment. Across all guidelines the lowest scoring domain was applicability and stakeholder involvement. Qualitative assessment showed that some guidelines adopt an unwavering disease orientated approach to assessing patient need. Guidance around continuity of care, out of hours care and after care was particularly poor in several guidelines. There was considerable heterogeneity in the evidence presented even amongst those guidelines that achieved high AGREE II scores.

Conclusion: Combined quantitative and qualitative assessment demonstrates the importance of rigorous guideline development. Whilst the variation in evidence presented could be a result of methodological heterogeneity in the development of guidelines, it raises important questions about the processes by which evidence, information and knowledge become transformed into clinical guidelines.

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1. Introduction

Improving care for patients with heart failure at the end-of-life is a national priority [1]. The overall long term survival rate is worse in patients with heart failure than for men with colorectal cancer or women with breast cancer [2]. Yet despite this, studies suggest that patients with heart failure are less likely to receive high quality end-of-life care compared to those who have a cancer diagnosis [3]. Over recent decades, a number of national and international organisations have developed heart failure guidelines to support clinicians in primary care improve the quality of care of patients with advanced heart failure. However, there has been no systematic evaluation of such guidelines to date in relation to end-of-life care.

One of the key criticisms of care for people with advanced progressive illness is that care has been based on medical diagnosis

rather than need [3]. This is a problem as it results in care that is both inequitable and not patient centred. The prior assessment of patient need has been identified as a marker of quality in the UK End-of-Life Care Strategy, in order to ensure patients receive care that is proactive and designed to meet patient need [4]. The “holistic patient assessment” tool within the Gold Standard Framework (GSF) toolkit suggests those domains which should be explored in order to deliver high quality care [5]. It follows that a key question is “do current guidelines support this approach, and if so how?”.

Given that the majority of care for those with chronic heart failure is co-ordinated and delivered in primary care it is important that the guidelines acknowledge role. Critiques of guidelines from a primary care perspective include how they ignore the conceptual basis of caring for those with advanced chronic disease in primary care [6]. For example, the limitations of single disease models in those with co-morbid disease and/or complex needs. Historically, guidelines have been built on research that has not been gathered in primary care populations, with the result that evidence is often weak when applied in this context. Indeed, many patients are frustrated by practitioners’ rigid use of guidelines for many conditions, and want care that is individually tailored [7].

The purpose of this study is to assess national guidelines using two complementary approaches, in order to identify whether guidelines

☆ The authors take responsibility for all aspects of the reliability and freedom from bias of the data presented and their discussed interpretation.

☆☆ This study was funded by the UK National Institute of Health Research (DRF-2010-03-66).

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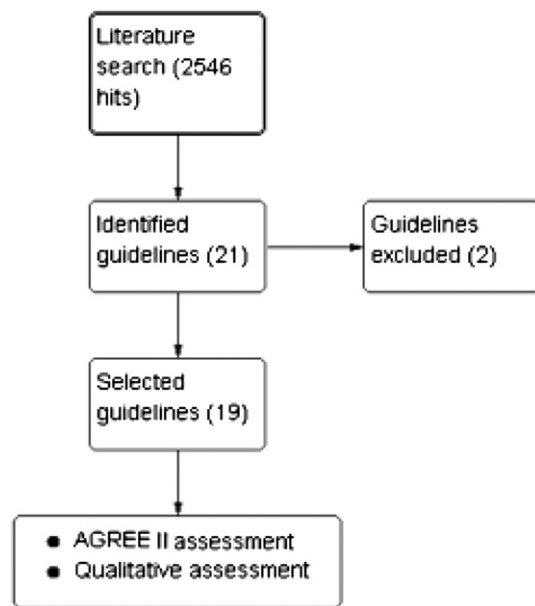


Fig. 1. Selection and appraisal of relevant guidelines.

support patient centred primary care. Selected current guidelines for the management of heart failure are reviewed using 1) a standard well validated generic guideline based assessment tool which provides quantitative ratings and 2) a qualitative thematic analysis to enrich the numerical assessment and enable comparison of the content of the guidelines. The review forms a part of a programme of research exploring patient needs in heart failure at the end-of-life.

2. Method

MEDLINE, Web of Science (ISI), EMBASE, and the Cochrane library were searched for recent (1996–2011) national guidelines using keywords such as “heart failure” “primary care” and “guidelines” (full search strategy available on request). Inclusion criteria were then applied to select the guidelines to be used in the review. Guidelines had to be national or international. Those guidelines that were not available in the English language were translated by a professional translator. The search was supplemented with a web search of guideline clearing houses and relevant national and international guideline producing organisations. Assessment was made on the published guidelines given that these are what primary care clinicians would read. Each guideline was assessed independently using the following approach (Fig. 1):

2.1. Quantitative assessment

The selected guidelines were independently assessed using the latest version of the Appraisal of Guidelines for Research and Evaluation tool (AGREE II) [8]. AGREE II consists of 23 key items in six domains. These include: scope and purpose: concerned with overall aim, specific clinical questions, and the target patient population (items 1–3); stakeholder involvement: focuses on the extent of representation of the views of its intended users (items 4–7); rigour of development: related to the process of synthesising evidence and methods (items 8–14); clarity of presentation: deals with language and formatting (items 15–17); applicability: pertaining to the organisational, behavioural, and cost implications (items 18–21); and editorial independence: concerned with the independence of the recommendations and conflict of interest (items 22–23).

For each domain, questions are scored on a 4-point scale from 4 (strongly agree) to 1 (strongly disagree) and then an overall percentage score is derived for each domain by summing all the scores of individual items and standardising the total as a percentage of the maximum possible score for that domain. This approach is similar to quality-assessment scoring systems used for assessing the quality of research papers in systematic reviews.

2.2. Qualitative analysis

The approach taken for qualitative analysis was adapted from that described by Hegarty et al. [9]. A data-extraction framework was devised based on the holistic needs assessment tool of the Gold Standards Framework. The holistic needs assessment defines key areas of patient need at the end-of-life as relevant to primary care – physical, emotional, personal, information and communication, control, out of hours, late (terminal) care and aftercare. The text of each guideline was then analysed using an approach based on thematic analysis of qualitative research data [9]. This was then applied to the guidelines and reviewed independently using this coding and assessment process. The coding process involved identifying where in a guideline a particular theme occurred, then summarising the text into a data extraction template. Assessment involved judging whether the theme was covered or not, and for some themes making a judgement about the completeness of the guidance itself. The qualitative assessment did not examine the strength of the evidence as this was assessed in detail using the AGREE II criteria.

3. Results

A total of twenty one chronic heart failure guidelines were identified. Two guidelines identified by the search process were excluded because they were either for a specific population or had been withdrawn from use. Nineteen national/international guidelines were included [10–28]. All guidelines had been published within the last eight years. Nine Guidelines were published in English – the remainder in their native language. Guideline length varied from 8 pages (Singapore) to 164 pages (Netherlands) resulting in considerable disparity in the amount of information presented. There were some cross-referencing between the guidelines selected – particularly amongst those guidelines that had adopted European Society of Cardiology (ESC) or National Institute of Clinical Excellence (NICE) guidelines as a framework. Rankings using the AGREE II assessment tool are shown in Table 1. England and Wales'

Table 1

The relative ranking of the selected guidelines according to the six AGREE II domains.

Country guideline	Scope and purpose	Stakeholder involvement	Rigour of development	Clarity and presentation	Applicability	Editorial independence
England and Wales [12]	89	89	96	100	92	92
Scotland [11]	72	78	92	94	79	92
Australia [23]	72	83	56	89	79	75
Europe [26]	81	52	84	83	68	86
Netherlands [10]	78	89	67	78	75	67
US (AHA) [15]	78	50	94	89	46	92
New Zealand [19]	89	72	75	100	63	50
US (HSFA) [27]	78	39	90	94	42	92
Canada [14]	67	67	58	100	50	92
Germany [28]	67	61	79	89	58	67
Brazil [18]	44	58	57	83	67	100
Northern Ireland [24]	56	44	90	83	67	50
Sweden [17]	56	56	58	72	58	67
Italy [13]	61	61	40	61	33	58
Denmark [22]	50	44	40	61	33	58
Japan [16]	61	39	48	61	38	33
Singapore [25]	56	39	40	81	38	17
Russia [21]	44	33	31	50	42	25
China [29]	39	28	35	33	21	33

% mean score of the two reviewers calculated according to the AGREE II scoring system. Maximum AGREE II score 100%.

Table 2

Qualitative appraisal of guidelines according to the Gold Standards Framework holistic needs assessment.

	Physical	Emotional	Personal	Social	Information	Control	Out of hours	Late care	After care
England and Wales [12]	Symptom control complementary therapy Compliance	Depression fears relationships understanding expectations	Inner journey patient/carer agenda quality of life	Benefits care for carers practical support	Within PHCT between professionals to and from patient/carer	Choice treatment options	Continuity	Patient aware comfort measures terminal care non urgent treatment stopped	Support team
Scotland [11]	Symptom control compliance prn medication	Depression understanding expectations	Patient/carer agenda quality of life	Practical support	Within PHCT between professionals to and from patient/carer	Advanced directives choice	Continuity communication to OOH medical support	Patient aware Terminal care rattle/agitation non urgent treatment stopped	Assessment/ audit
Australia [17]	Symptom control complementary therapy compliance PRN medication	Depression fears relationships understanding expectations	Patient/carer agenda quality of life	Care for carers	Within PHCT between professionals to and from patient/carer	Advanced directives choice treatment options	Continuity medical support	Patient aware rattle/agitation non urgent treatment stopped drugs/equipment	–
Europe (ESC) [26]	Symptom control compliance PRN medication	Depression fears relationships understanding expectations	Inner journey spiritual needs quality of life	Practical support care for carers	Within PHCT between professionals to and from patient/carer	Advanced directives choice place of death treatment options	Continuity medical support	Patient aware terminal care comfort measures non urgent treatment stopped	Family support support team
Netherlands [10]	Symptom control compliance PRN medication	Depression fears understanding expectations	Patient/carer agenda quality of life spiritual needs	Care for carers practical support	Within PHCT between professionals to and from patient/carer	Advanced directives choice place of death treatment options	Continuity medical support	Patient aware terminal care drugs/equipment non urgent treatment stopped	Family support support team
US (AHA) [15]	Symptom control compliance PRN medication	Understanding expectations	Inner journey patient/carer agenda quality of life	–	Within PHCT between professionals to and from patient/care	Advanced directives treatment options	Continuity medical support	Patient aware terminal care non urgent treatment stopped	Assessment/ audit
New Zealand [19]	Symptom control PRN medication	Depression fears understanding expectations	Inner journey patient/carer agenda quality of life	Benefits care for carers practical support	Within PHCT between professionals to and from patient/carer	Advanced directives choice place of death treatment options	Communication to OOH medical support	Patient aware terminal care rattle/agitation non urgent treatment stopped	Family support bereavement follow-up support team

US (HSFA) [27]	Symptom control compliance PRN medication	Understanding expectations	Patient/carer agenda quality of life	Practical support	Between professionals to and from patient/carer	Advanced directives choice place of death treatment options	Continuity communication to OOH medical support	Patient aware drugs/equipment terminal care non urgent treatment stopped	Family support
Canada [14]	Symptom control compliance prn medication	Depression fears relationships understanding expectations	Inner journey patient/carer agenda quality of life	Benefits care for carers practical support	To and from patient/carer	Advanced directives choice place of death treatment options	Continuity communication to OOH medical support	Terminal care rattle/agitation	Family support support team
Germany [28]	Symptom control compliance	–	–	–	–	–	–	–	–
Brazil [18]	Symptom control complementary therapy compliance	Depression relationships	Inner journey quality of life	–	–	–	–	–	–
Northern Ireland [24]	Symptom control compliance	Depression understanding expectations	Patient/carer agenda quality of life spiritual needs	Benefits practical support care for carers	Within PHCT between professionals to and from patient/carer	–	Medical support	Terminal care non urgent treatment stopped	Assessment/ audit
Sweden [17]	Symptom control	Understanding expectations	–	–	–	Between professionals	–	Terminal care drugs/equipment non urgent treatment stopped	Assessment/ audit
Italy [13]	Symptom control	Understanding expectations	inner journey patient/carer agenda quality of life	Practical support	To and from patient/carer	–	–	–	–
Denmark [22]	Symptom control	–	–	–	–	–	–	–	–
Japan [16]	Symptom control compliance	Depression	Quality of life	Benefits care for carers	To and from patient	–	–	Comfort measures	Family support support team
Singapore [25]	Symptom control	–	Patient/carer agenda	Benefits	–	–	–	Rattle/agitation drugs/equipment	Assessment/ audit
Russia [21]	Symptom control	Depression	Quality of life	–	–	–	–	–	–
China [29]	Symptom control compliance	–	–	–	–	Choice	–	Terminal care	–

(NICE) guidance scored highest across all five domains, followed by Scotland (SIGN), Australia, Europe (ESC) and the Netherlands. Ten guidelines failed to score over 50% in all six domains – Brazil, China, Denmark, Italy, Japan, Northern Ireland, Russia, and Singapore. Across all guidelines the lowest scoring domains were applicability and stakeholder involvement.

Thematic analysis of each guideline against using the holistic needs assessment extraction framework is shown in Table 2. No guideline demonstrated complete coverage of all domains. Results specific to each domain include:

3.1. Physical needs

Most guidelines recommended the need for physical assessment at the end-of-life, for many this was in the context of seeking specialist clinician/palliative care input for intractable symptoms. Most guidelines covered the management of specific symptoms e.g. dyspnoea. However, the more general complaint of “fatigue” was poorly covered. Only England, Wales, the Netherlands and ESC recommended the use of validated tools or guidelines for symptom management. For medication reviews the emphasis in many guidelines was on compliance rather than stopping non-essential medications at the end-of-life. Only two guidelines made recommendations relating to adverse effects of medications and how this should be managed.

3.2. Emotional needs

Most guidelines focus on the identification and pharmacological treatment of depression. Only three guidelines discussed the use of non-pharmacological interventions for treating depression in chronic heart failure. Those guidelines that covered the patient's own understanding of expectations generally focus on issues of resuscitation, switching off implantable defibrillators and communicating prognosis. Only the Netherlands' guideline explicitly discussed the importance of exploring patients' fears.

3.3. Personal needs

Only five guidelines covered the importance of addressing spiritual and religious needs. In contrast, twelve covered the importance of exploring the patient's inner journey. Those guidelines that focused on quality of life generally highlighted that heart failure is associated with a poor quality of life. Only one guideline explicitly stated that improving quality of life should be the primary concern at the end-of-life.

3.4. Information and communication

Much emphasis was placed on the need for communication between clinician, patient and carer. However, few guidelines discussed what the content of such communication should be. Only three guidelines indicated that this information should be individualised and anticipatory. A small number of guidelines highlighted the need to be aware of cultural issues in relation to communication.

3.5. Control and autonomy

Those guidelines that discussed “choice” generally did so in relation to supporting patient-centred care. One guideline discussed choice in relation to drug treatment preferences. Several guidelines discussed the use of advanced directives, living wills or advanced care plans. Only a small number of guidelines outlined what contingencies these documents should include in relation to heart failure e.g. cardiac arrest. Only four guidelines explicitly discussed place of death. Each highlighted that palliative care should be available where the patient is. Only one highlighted that many patients are not aware that palliative care can be delivered at home.

3.6. Out of hours

The domain of “out of hours” was particularly poorly covered by all guidelines. Whilst some emphasis was placed on support for carers there was little discussion in relation to the delivery of medical care. Specific issues around co-ordination of care, place of death, drugs and equipment, and resuscitation orders in the community were not covered.

3.7. Late (terminal) care

Not all guidelines addressed late care. Those that did emphasised that heart failure has an unpredictable disease trajectory. In relation to stopping non-urgent treatment some guidelines emphasise that decisions to stop routine medication, such as ACE inhibitors should be made on the basis of intolerance, rather than be the aim of treatment itself. Others guidelines stated that any medication that detracts from a peaceful death should be stopped. In addition, a number of guidelines also outline the importance of deactivating pacemakers and implantable cardiac defibrillators in the terminal phase.

3.8. Aftercare

Only one guideline explicitly discussed bereavement support for family members and caregivers. Six guidelines covered the importance of family support, emphasising the importance of psychosocial support. No guideline explicitly discussed support teams e.g. bereavement support services, and contacts for the timely removal of equipment. Five guidelines covered the importance of audit and assessment. This was invariably set in the context of identifying quality indicators.

4. Discussion

The combined quantitative and qualitative assessment of national/international chronic heart failure guidelines demonstrates considerable heterogeneity in the evidence presented in relation to needs at the end-of-life. This variation was seen even amongst those guidelines that achieved a high score on the AGREE II criteria. Given that all guidelines had access to a similar (if not the same) evidence base, this was surprising. Whilst this could simply be a result of methodological heterogeneity in the development of guidelines, it raises important questions about the social and organisational processes by which evidence, information and knowledge become transformed into clinical guidelines. For example, health care system structure, patient expectations and the balance of power within those stakeholders involved. This is particularly an important point given the considerable challenges faced when undertaking research at the end-of-life.

Across all guidelines the lowest scoring domains were those of applicability and stakeholder involvement. These domains relate whether i) existing barriers and facilitators that impact on the application of a guideline have been considered and ii) whether the relevant professions had been involved in the guideline development, whether the view and preferences of the target population had been sought and whether the target users of the guideline are clearly defined. Issues surrounding applicability and stakeholder involvement are not confined to heart failure guidelines and have been highlighted by others [9]. It was interesting to note that those guidelines that did score highly for stakeholder involvement adopted a more patient-centred approach. For example the guidelines from the Netherlands emphasise that “starting point for optimal care is that which is person centred”.

The qualitative assessment showed that many guidelines adopt a largely disease-orientated approach to assessing the needs of patients with heart failure at the end of their lives. Similarly, many guidelines offered little support for a ‘biographical’ or person-centred approach which may be due to a paucity of evidence. Alternatively, selecting studies only by their place in a hierarchy of designs could have a

similar effect. International guidelines, such as those developed by the ESC, reflected important differences in end-of-life care legislation between countries. They exercised caution when presenting guidance on subjects that are not consensual amongst all countries. For example, euthanasia is illegal in many but not all countries.

5. Study limitations

The two authors that proposed the AGREE II score both were from the UK and consequently some bias may be present. Potential limitations of the AGREE II tool have previously been published [8]. Limitations relating to the GSF tool itself include that the instrument examines quality management at a practise level rather than at the level of the individual doctors, at which most guidelines are aimed. The review did not include other related policy developments, for example, the World Health Organization guidance on palliative care [30].

6. Implications for clinical practise and future research

Guidelines attempt to synthesise a substantial body of knowledge into a coherent and manageable set of recommendations to support clinical decision making. The complexity of addressing needs at the end-of-life in heart failure means that short guidelines are always likely to remain limited in their relevance and applicability to primary care, whilst longer ones many not be read by busy clinicians – clearly a balance is required. New initiatives such as “NICE pathways” may present an opportunity to address this concern. With this in mind, the ideal heart failure pathway would also recognise that:

- Adopting a person-centred approach to guideline development is key to ensure that all bio-psycho-social needs are addressed.
- Guidance around continuity of care needs to be strengthened – current guidance around out of hours care and after care is particularly poor.
- Greater consideration is required on how to combine evidence from primary palliative care given its inherent methodological complexity.

Finally, in terms of future primary care research, there remains a distinct lack of longitudinal evidence exploring patient self-perception of complex needs. A more critical approach to future studies looking at individual experiences of heart failure patients is required, in order to identify where and when existing health care approaches are, and are not, applicable. A comprehensive understanding of complex needs over time would facilitate and determine the appropriateness of current health policy proposals for end-of-life care.

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